Giving Back

Christine Healy, Licensed Clinical Social Worker

What do those words really mean? And how many different ways are there to give back? Some people are motivated and in the position to donate money to the Moffitt Foundation. Others may give back by donating their time.

After a diagnosis of cancer, many patients and caregivers spend a lot of time here at Moffitt. It may not always feel like a choice, but a requirement, if they have a chance at cure or even survival. While here, they are able to observe and get to know other patients, caregivers and staff. They connect with others in a way that is unique because of their common experiences. This connection has lasting effects, even after the patient has finished treatment. Patients and caregivers often develop relationships with Moffitt team members and when treatment ends they may miss these connections.

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**October – November**

**Arts In Medicine Studio**  
813-745-8407  
Open Arts Studio: relax, create, express, discover and share inspiration  
MCC – Every Mon. - Fri., 9:30 a.m.–4 p.m., Arts Studio, 3rd floor, elevator B  
MKC – Every Mon. – Fri., 8:30 a.m.–5 p.m., Patient and Family Center, 1st floor, by Publix Pharmacy

**AYA Lounge Night**  
813-745-4736  
MCC – Every second and fourth Thur., 5–7 p.m., AYA Lounge, 4th floor, use elevator C

**Gentle Restorative Yoga**  
813-745-6052  
MRC – Every Tues., 12–1 p.m., Yoga Room

**Meditation/Relaxation Classes**  
813-745-6052  
MCC – Every Wed., 12:15–1 p.m., Day Room, 5th floor, use elevator C

**Meet the Expert Series**  
813-745-4710  
Cancer experts share information on various topics  
MCC – Every Mon. – Fri., 10–10:30 a.m., Patient Library & Welcome Center, 2nd floor, elevator B  
MKC – Thursdays, 10:30–11 a.m., Patient and Family Center, 1st floor, by Publix Pharmacy

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**OCTOBER**

**Tue., October 8 and 22**  
**MKC Caregiver Coffee Connection**, 9–10:30 a.m., Gruden Huddle Room, 1st floor.

**Wed., October 9**  
**Tools To Quit**, free quit smoking class and free nicotine patches, 2–4 p.m., Muriel Rothman Building, Owl’s Den Meeting Room, 1st floor, 813-745-8811 or TobaccoTreatment@Moffitt.org

**Thur., October 10, 17 and 24**  
**Coffee Connection**, 9:30–11:30 a.m., MCC, Owl’s Den Meeting Room, 1st floor, (around the corner from Blood Draw)

**Wed., October 16**  
**Pancreatic Cancer Event**, local group of pancreatic cancer survivors supporting each other and creating awareness, 6:30-8 p.m., MCC, Owl’s Den Meeting Room, 1st floor, 813-745-1342 or Kim.Murphy@Moffitt.org

**Wed., October 16**  
**Music & Art á la Carte**, 1-2 p.m. event featuring a Musician-in-Residence paired with one of our Artists-in-Residence, 1-2 p.m., McKinley Outpatient Center, 3rd floor, 813-745-1836.

**Wed., October 16**  
**Music & Art á la Carte**, event featuring a Musician-In-Residence paired with one of our Artists-In-Residence, 1:30 p.m., Moffitt International Plaza, Lobby, 1st floor, 813-745-1836.

**Mon., October 17**  
**An Evening at Moffitt, Focusing on Thyroid Cancer Awareness**, presentation for Thyroid Cancer Awareness month, 6–8 p.m., need RSVP, ThyroidCancerEvents@Moffitt.org
Some decide that a yearly scan or surveillance is all they ever want to experience in terms of returning to a cancer center. But others are pulled back in a different way. They recognize the passion, support and commitment they experienced here and they want to be a part of it.

Those that do return have a special kind of courage. They have made a decision not to look at cancer in the rearview mirror but confront its memory head on. They make a commitment to show up weekly and perform a task or connect with other patients and caregivers who are in active treatment. They understand lending an empathic ear, sharing their own past experiences or just passing the time talking about everyday things helps to create a comfortable environment in an otherwise, sometimes uncomfortable place.

Giving back is paying it forward. It is understanding and acknowledging how important it is to help ease the burden of patients, family members and even staff because you remember. Recognizing the need to contribute even when you’re not always sure of your own motivations but feeling that draw to return.

In this issue of Partners, you will be meeting many of our volunteers, all past and sometimes current patients and family members, who have chosen to take that step back while they are moving forward. They use their unique skills to make something amazing out of their cancer experience. And we are a better cancer institution because of them.
Message from the Co-Chair

Debbie Phillips, Co-Chair
Patient and Family Advisory Council

My sister-in-law Tamara was a 42-year-old mother of three when she was diagnosed with Acute Myeloid Leukemia; one day she was a beloved teacher in her classroom – and the next day she was in the hospital fighting for her life.

From the moment we arrived at Moffitt we felt we were in the right place to fight this battle. The doctors, nurses and technicians were all so knowledgeable, caring and compassionate and our family was not only welcomed, but was made to feel we were an important part of the process. Moffitt welcomes family participation in the caregiving process because they understand that cancer impacts the entire family – and that the support of family and friends is a powerful force in a patient’s recovery.

This year marks the 10th anniversary of my sister-in-law’s AML diagnosis. That first year was the most difficult for our family, but it was also a year that brought enormous lessons in caring, connection, and the power of hope. Not a day went by without someone offering Tamara and our family encouragement, support, love and prayers. Tamara remembers that she really felt embraced by everyone, and she says she never felt alone in her journey.

Given our experience, I had a strong desire to “give back” to the institution that enveloped our entire family and to the folks who saved my sister-in-law’s life. I joined Moffitt’s Patient and Family Advisory Council, and it has been incredibly rewarding to sit alongside Moffitt’s administrators, staff and faculty as we work to find solutions that enhance the patient experience. Moffitt truly welcomes our perspective, and our patients and caregivers have a voice in all we do!

For more information about the Patient and Family Advisory Council, please email PatientAdvisors@Moffitt.org or call 813-745-2963.

Patient and Family Support Groups

The following support groups are offered at Moffitt Cancer Center.

To learn more about any of the support groups offered, including times and locations, please call the Social Work Office at 813-745-8407.

Cancer Support Group
Support group for patients with any cancer diagnosis. Meets every Tuesday, 1-2 p.m., Magnolia campus, 5th floor lounge of the hospital. Use elevator C.

Cutaneous T-Cell Lymphoma Support Group (CTCL)
Support group for CTCL patients. Meets every 3rd Thursday, 4:30-5:30 p.m., McKinley campus, 4th floor. For information call 813-745-3583.

Family and Friends Support Group
Support group for family members, friends and caregivers of cancer patients. Meets every Tuesday, 1-2 p.m., Magnolia campus, 5th floor of the hospital, room 5140 A. Use elevator C.

Metastatic Breast Cancer Support Group
Support group for patients with Stage IV metastatic breast cancer. Meets weekly for six-week sessions throughout the year, from 10:30-11:30 a.m., McKinley campus. For information call 813-745-8407.

Breast Cancer Connection
Support group for all patients with breast cancer. Meets the first Tuesday of every month, 6-7 p.m. at the McKinley campus, Gruden Huddle Room, 1st floor.

Families First
A bi-monthly therapeutic program offered on Saturdays for patients who are parents and their children (ages 5-18).

Finding Balance with Cancer
A 4-week stress reduction program jointly offered by the Integrative Medicine Program and Social Work. Patients and caregivers learn meditation through group discussion, guided practice and CDs for home use.
Your Courage Inspires Us

Jack Kolosky, Executive Vice President and Chief Operating Officer

We see courage in action every day at Moffitt, and it has become a theme that provides inspiration to all of our team members. No one embodies that spirit more than Moffitt’s Patient and Family Advisory Council (PFAC). This group is made up of individuals who have experienced the treatment of cancer either as patients and/or as family members. Those difficult days alone inspire us. In addition to their personal journeys, PFAC members contribute countless hours of their time, talents and observations to make things better for all patients. Even more remarkable is the passion they bring to their many efforts. No one expects to have cancer, yet they chose to come to Moffitt to manage this dreaded disease. And now they serve other patients, not with clinical care but with a passion to improve the situation for all patients. Their contributions and accomplishments combined with their personal courage are truly remarkable.

Working with the PFAC continues to be an amazing journey. Moffitt’s Executive Leadership will continue to be open to their frank, open and wise advice for the betterment of all patients. There are not enough ways to say thank you to each and every one of the members of PFAC for all of their contributions.

If you would like to learn more about the Patient and Family Advisory Council, please email PatientAdvisors@Moffitt.org or call 813-745-2963.

YOUR VOICE MATTERS

Learn How Sharing Your Voice Can Impact the Patient Experience

Ask about the Patient and Family Advisory Council at PatientAdvisors@Moffitt.org.

Coffee Connection

Every 2nd, 3rd, 4th and 5th Thursday of the Month
9:30–11:30 a.m.

Moffitt’s Magnolia Campus
1st Floor, Owl’s Den Meeting Room
What It Means to Give Back

“I had and still have an army of supporters with my amazing family and friends, but it’s a different kind of support offered by another patient who has walked the path before; someone who is still thriving. I am a “scout” who has gone ahead on a mission to look for dangerous pitfalls and then return to help people know what they might find along their journey and I made it through so far. I volunteer as a peer visitor on Thursday morning Coffee Connections at Moffitt, volunteer in the Patient Library and Welcome Center and serve on the Patient and Family Advisory Council. ”

– Zoe Marcus, Peer Visitor, Patient and Family Advisory Program

“I call giving back to Moffitt my privilege of survivorship. Among other volunteer duties, I conduct Patient and Family Orientations. It is my mission to relieve some of the anxiety the patients and their families feel when they are frightened and confused with a new diagnosis. A grateful hug confirms my efforts made a difference. Again, it is my privilege!”

– Jane Garland, Patient Advisor, Patient and Family Advisory Program

“When I volunteer in Moffitt’s Patient Library and Welcome Center, I am motivated to work hard every day. I stay focused and am confident in what I’m doing.”

– Emily Ramos, Pepin Center

“Moffitt’s dedication and commitment to fighting cancer were bright lights of hope for my husband, Ralph, and me during his almost-four-year battle with pancreatic cancer. As part of the Patient Family Advisory Program, my goal is to reflect Moffitt’s pledge and to be that bright light of hope to patients and caregivers as they walk their cancer journey. I serve as a peer visitor and visit patients and families in the infusion center.”

– Cathy Tack, Peer Visitor, Patient and Family Advisory Program

“When I went through treatment at Moffitt, the support and care I received was more than I could ask for. It made the difference in my recovery. When I was offered the chance to be a part of that group and help others, I felt delighted and honored. I volunteer to help other young adults facing cancer through Moffitt’s Adolescent and Young Adult (AYA) Program.”

– Megan Wing, Patient Advisor, Patient and Family Advisory Program
“I volunteer because I have been encouraged and helped by so many other patients that also have my type of cancer. I enjoy talking with patients and caregivers and hope that even more kindness and encouragement is passed along between all of us here at Moffitt.”

– Michelle Sullivan, Peer Visitor, Patient and Family Advisory Program

“I enjoy volunteering as a family advisor because I feel like I am making a difference in the lives of patients and caregivers who are facing challenges with various diagnoses of cancer and treatments. I was a caregiver for my mother and by volunteering at Moffitt, I feel like I can pay it forward. I present the Patient and Family Orientation sessions and I serve on the PARTNERS editorial committee.”

– Laurie Reed, Family Advisor, Patient and Family Advisory Program

“Based on my personal cancer experiences and Moffitt volunteering, I was invited to join Imerman Angels to reach out to a family caregiver after losing a loved one to cancer. I took a deep breath, picked up the phone and dialed and then a mutually beneficial relationship developed. I strongly encourage others to get involved.”

– Ken Susalla, Peer Visitor, Patient and Family Advisory Program

“I volunteer by connecting with patients and caregivers in the Blood and Marrow Transplant Clinic. No one really knows what a good feeling is until they do something meaningful for someone. Our work is meaningful. I sometimes almost feel guilty for feeling so good.”

– Don Owen, Peer Visitor, Patient and Family Advisory Program
Hearing a patient or caregiver’s personal, true story provides an opportunity for Moffitt team members to see the patient or caregiver as a person including their goals, values, struggles and successes. Their stories have the power to adjust the lens from which we view the importance of what we do in our roles every day.

Moffitt Patient-Researcher Forums (PRFs) began in April 2018. Upon realizing that she might benefit from learning about ongoing research efforts for her cancer, Moffitt’s contracted acupuncturist, Liem Quang Le, DAOM, suggested that his patient, Danielle DeCleene, take a tour of a melanoma research lab. Dr. Le arranged the tour with Eric Lau, Ph.D., Assistant Member, Department of Tumor Biology. DeCleene toured Dr. Lau’s lab and talked with his researchers. DeCleene learned about the researchers’ efforts in studying melanoma, which gave her hope. What occurred during their time together was an organic sharing that was impactful for everyone involved. DeCleene shared her story of being diagnosed with stage IV melanoma and brain metastases at the age of 32. A reminder that the cancer that the researchers were studying had a face – a person connected to it. For weeks following, productivity and researcher motivation in the lab

With the support of leadership, clinicians, organizers, researchers and patient advisors, Moffitt has held 10 monthly PRFs, which have positively impacted many researchers as well as patients and caregivers.

Patient-Researcher Forum Participants
increased, and DeCleene felt listened to, empowered and left more hopeful knowing this talented and dedicated group of researchers was working for her.

Drs. Le and Lau knew that this experience needed to be replicated to benefit more researchers and more patients and reached out to the Patient and Family Advisory Program. With the support of leadership, clinicians, organizers, researchers and patient advisors, Moffitt has held 10 monthly PRFs, which have positively impacted many researchers as well as patients and caregivers.

“Getting to relate with actual patients and hearing about their trials, tragedies, and triumphs have given me a new perspective and motivation. Sometimes I feel like I’m just a small part of the machine working in cancer research, but seeing the real-world impact that every advance has on patients was a great reminder that what I do actually matters. The patient-researcher forum has re-inspired me to continue to do my best to advance our research in treatment and prevention for cancer patients.”

— Matt Mercurio, Research Associate
Department of Tumor Biology

“Touring a lab dedicated to the prevention and cure of cancer was fascinating and filled me with hope that someone is working on my behalf! Sharing my stories of treatments and remission with researchers and hearing why they do what they do left me enthusiastic for where treatments for cancer are going.”

— Patti Halula, Co-Chair, Patient and Family Advisory Council

During each PRF, patients and caregivers tour a lab and learn about newly developing research initiatives for their cancer type. Meanwhile, in a meeting room, up to 20 researchers are briefed by clinicians on the clinical diagnosis and treatment of the cancer being featured at the particular forum. Then, over lunch, the patients and caregivers share their stories about what they’ve experienced, including their treatments, hurdles, side effects, setbacks, recurrences and successes. Researchers see first-hand why their work is so important. Patients connect with the researchers and learn not only what they’re studying, but also their personal motivations for careers in cancer research.

Although data isn’t needed to see the positive impact the PRFs are having, researchers love to collect data. Thus, we are collecting data via follow up surveys with the help of Moffitt’s Health Outcomes and Behavior department.

Special thanks to each patient and caregiver who has courageously shared his/her story to impact research at Moffitt. It’s a lot to ask of anyone to relive their cancer journey, and we would not ask if it was not mutually beneficial for our patients, caregivers, and Moffitt clinical and research team members. The PRFs serve as a reminder of Moffitt’s strong and growing culture of patient- and family-centered care, including collaborating with our patients and families who want to give back to Moffitt.

To learn more about this program please view this brief video https://vimeo.com/twostoriesmedia/review/333491723/e705ab4291. If you would like to learn about the many ways to partner with Moffitt, including sharing your story, please email PatientAdvisors@Moffitt.org.
I have always considered myself a healthy and physically fit woman having completed three half-marathons with my daughter after I had turned 55. In fact, I had just run six miles on Christmas Eve, when five days later, I had a seizure at work and was diagnosed with two brain tumors, the result of a rare lymphoma. But that is not my story for today. Today, I write about the people who took me to recovery. There are too many to mention in addition to my incredible husband and daughters, but for starters Dr. Peter Forsyth, Dr. Ernesto Ayala and their remarkable staff. Plus, the nurses I became friends with along the way.

After successfully completing chemotherapy I was recommended and admitted for a stem cell transplant. Per protocol, I was in a controlled setting with a U-shape area between the doors to the rest of the Moffitt world. An important part of treatment was ensuring that I remained active and moving around to avoid any additional complications. This is where I met physical therapist Sarah Rahilly. She would come to my room with an amazing smile on her face and motivated me to put my sneakers on and walk the “U.” We would talk about many things, but one in particular, was her preparation to complete an Iron Man competition. I told her how delighted I was for her and that when I got through with all this treatment that I was going to do another half marathon. She smiled her usual smile and said, “Let me know and I will come do it with you.” As time went on I tracked Sarah’s Iron man on the app. I was so proud of her accomplishment, and I kept in touch with her with texts when I got those clean MRIs.

A year and a half after my transplant, my daughter and I signed up for the “Donna” half marathon, which was fitting because that is my name and it is for breast cancer research and awareness. I waited to let Sarah know I was going to participate until after I had reached five miles in my training. I received a text encouraging me to continue on. I let her know when I was at eight miles and she responded with a text of encouragement usually a cute emoji. Then I received a text, unexpected, but the kind that completely touches the heart, Sarah had signed up to run the race with me in Jacksonville. The day of the race she told me she was running by my side and she was going to cross the finish line with me (despite me telling her she would have to run slow which actually is not that easy). She reminded me of those walks in the stem cell hallway and how she had said if I ran another half she would run it with me. The rest is now history. We ran the half-marathon in two hours and 33 minutes (which pleasantly surprised me). Sarah stopped to put the medal around my neck and the day became such an amazing memory of faith, love, support, and kept promises on both sides. The day I was diagnosed, my daughter said with positive affirmation that we would share this memory. Sarah reminded me of what she considered a promise in the hallways of the stem cell unit, and as if it couldn’t get any better Dr. Ayala showed up to run the race with us. Moffitt is family to me and this is just one more reason why.

NOTE: Shout out to Moffitt nurse Sidney Resmondo who trained to run with us but was there in spirit and texts along the way.
Patient Advisors Improve Patient Education Materials

Vicki Vann, MS, APRN, Patient Education Department

Our patient advisors provide a unique patient perspective into healthcare experiences at Moffitt. In 2005, Moffitt launched the Patient and Family Advisory Program. One of the main goals of the program was to ensure patient and family input and partnership in all things Moffitt.

Having been through their own cancer experience, patient advisors provide insight by helping review and edit education material. Their input contributes to safe clinical care by making this content easy to understand for patients, family members and caregivers.

As new patient education material is developed at Moffitt, the Patient Education Department has a formal process to vet these documents. We rely on patient advisors to help us review and edit content, determine if medical terms are understandable, determine if content is too long or disorganized, review titles and captions, and help us decide if photographs or visual aids are appropriate. This process allows advisors to have direct input into information that may affect patient care.

Reviewing patient education material and providing feedback is an important role for patient advisors. We sincerely thank those who have shared their insight and experience as we continue to develop education material.

To learn more about how to become a patient or family advisor, please call 813-745-2963 or email PatientAdvisors@Moffitt.org.

Did you know that Moffitt has been awarded “Leader” designation for Health Care Equality by the Human Rights Campaign for seven years in a row?

To ensure Moffitt is an inclusive place for everyone, we are seeking LGBTQ+ patients and their family members to serve as advisors. For more information, call 813-745-2963 or email PatientAdvisors@Moffitt.org.
Seek And Speak Your Story

Robin Gordon, Patient Advisor, Patient and Family Advisory Program

When I decided to volunteer at Moffitt in 2010, I did not know what to expect. I only knew two things: one, that I wanted to deal directly with patients, and two, that I wanted to do something that utilized what I considered to be my assets: being a survivor, being a good communicator, and being a good listener. I was fortunate enough to become part of the Patient and Family Advisory Program. I loved the work of being a peer; meeting families at the weekly coffees and listening to patients in the clinic waiting room. But soon after starting this work, my supervisors, Christine Healy and Kim Buettner, started to ask about my professional skills, which I did not know could be put to use at Moffitt. I am a theater director and actor. They asked me to come up with an idea for the entertainment segment of a breast cancer conference. I created a short theater piece written and performed by patients. I did it again the next year. Then I was tapped, along with five Moffitt employees, to be trained to lead the Seek and Speak Your Story workshops at Moffitt.

Co-facilitating the Seek and Speak workshops has been not only a highlight of my volunteering, but also of my life. When patients and caregivers open their hearts to me and share their personal experiences, I feel both the tremendous honor and the awesome responsibility of shaping their stories with respect and care. I am so grateful to the Patient and Family Advisory Program for not only allowing me to be part of their mission to provide patient-centered care, but also for recognizing and utilizing my talents in a way that gives my life purpose and validates my entire cancer journey.

To learn more about Seek and Speak Your Story, email PatientLibrary@Moffitt.org or call 813-745-7618.